

# SUFFERING AT THE END OF LIFE

The State of the World



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## INTRODUCTION

Death is inevitable for us all. However, our experience of dying may vary considerably depending on factors such as the cause of our death, whether we have family or friends to care for us, where we live in the world and the availability of good health care.

Many people are more afraid of pain and suffering than of death itself. But great suffering is not inevitable; it can be alleviated by hospice and palliative care. This type of care can help patients and families affected by terminal illness.

Our vision is of a world in which the best possible care is available to all people at the end of life, whatever the circumstances. It is essential that individuals, organisations and governments recognise the potential of palliative care to alleviate pain and distress, and work together to make such care available to everyone who needs it.



A photograph showing a palliative care nurse, a woman in a red and black sari, sitting on the floor and holding the hand of an elderly, thin man with a grey beard. The man is wearing a patterned dhoti. They are in a simple, rustic room with a thatched roof and a mud wall. The nurse is looking at the man with a concerned expression. The text "It should be the right of every individual to have help and support at the end of life. Will you help to make it happen?" is overlaid in white.

It should be the right of every individual  
to have help and support at the end of  
life. Will you help to make it happen?

A PALLIATIVE CARE NURSE IN INDIA VISITING A PATIENT AT HOME, SHOWING THE POVERTY THAT MANY SUCH PATIENTS LIVE IN

## WHAT IS PALLIATIVE CARE?

Palliative care was defined by the World Health Organization in 2002 as:

“...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.”

Palliative care includes:

- Care for the patient and family or closest supporters.
- A multi-professional, team approach.
- Relief from pain and other distressing symptoms.
- Attention to emotional, spiritual and psychological as well as physical needs.
- Maximising the quality of remaining life.



## SECTION ONE

### SUFFERING AT THE END OF LIFE – IS IT INEVITABLE?



**DANIEL AND HIS WIFE**

#### **DANIEL'S STORY\***

Daniel was an 81 year old Polish Jew who came to Uruguay after World War II. He was aware that he had advanced lung cancer and complained of pain and breathlessness. He asked for help to end his suffering and his life explaining that he had suffered so much during his incarceration in a concentration camp in Poland during the war that he did not want to endure any more.

The palliative care physician said he understood but proposed an alternative solution. He explained that symptom control and morphine for pain control would help and promised the support of the palliative care team. The doctor described how their role could be compared to that of lighthouses - standing firm and showing the way, even in the worst conditions. Lighthouses offer useful signals but everyone still has to make their own trip in the knowledge that there will be stormy as well as fair days. In other words, whatever the sick person's experience, the advice and support of the palliative care service would always be available.

Daniel agreed to try this approach and once he had experienced relief from his pain and breathlessness, did not ask again about measures to end to his life. The doctor taught Daniel's wife how to administer the pain killing drugs thus empowering her and including her as a valuable member of the palliative care team.

**STORY PROVIDED BY DR YANNEO, PALLIATIVE CARE PHYSICIAN WORKING IN URUGUAY.**

\* Daniel's real name has been changed to protect his anonymity. This process has been applied to other individuals whose story is told in this publication, unless they have specifically requested that their real name is used.

## **SECTION ONE: SUFFERING AT THE END OF LIFE – IS IT INEVITABLE?**

### **THE SCOPE OF PALLIATIVE CARE**

Over a million people die each week across the world <sup>(1)</sup>. A significant proportion will have a progressive and life-threatening condition such as cancer or AIDS. These illnesses bring the lives of many of the sufferers to a premature and painful end.

Over 70% of patients with advanced cancer or AIDS experience severe pain<sup>(2)</sup>. With palliative care, most of this pain can be controlled if appropriate clinical guidelines are followed and effective drugs, including opioids such as morphine, are available.

Modern palliative care started in the UK in the late 1960s and has traditionally focused on those with cancer at the end of life. It is now increasingly recognised as an essential aspect of HIV clinical care <sup>(3)</sup>, and it is also used for patients with neurological disorders including motor neurone disease and multiple sclerosis, heart disease and respiratory disorders.

Palliative care for children and adolescents covers a wider spectrum of disease than for adults, and may last for many years.

### **FACTS AND FIGURES**

- Over 10 million people are diagnosed with cancer every year. <sup>(1)</sup>
- 6 million people die from cancer every year. <sup>(1)</sup>
- 3 million people died from AIDS in 2003. <sup>(4)</sup>
- 5 million people acquired the HIV virus in 2003. <sup>(4)</sup>
- 42 million people are currently living with the HIV virus worldwide, 29 million of these in sub-Saharan Africa. <sup>(5)</sup>

## SECTION ONE: SUFFERING AT THE END OF LIFE – IS IT INEVITABLE?



**JENICA AND HER BROTHER NICHOLAS**  
**DRAWINGS BY NICHOLAS**



### JENICA'S STORY

Jenica, at the age of 4 weeks, was diagnosed with leukaemia. Her initial plan of care focused on getting her leukaemia into remission in anticipation of a bone marrow transplant, which provided the only hope for long-term survival. Palliative care principles, concerned with relieving pain and other symptoms and providing support for the family, were an integral part of this plan.

Jenica received intensive chemotherapy and later a bone marrow transplant, during which time she and her mother spent long periods in hospital. Her brother Nicholas was her bone marrow donor, as well as her best friend and companion.

Initially Jenica did well, returning home as a happy active child. At the age of 15 months, however, the leukemia returned. She returned to hospital accompanied by her family who prepared for her last days of life. During this time Nicholas had the opportunity to talk about his sadness as well as to play with supportive friends, family and staff. On her day of death, Jenica's family were with her. They held her and told stories. After Jenica died, the hospital staff started a memory box for Jenica's family. Together, the nurses and the family placed some items in the box including a lock of Jenica's hair, her footprints, her dummy and a drawing dedicated to her from her brother.

**STORY PROVIDED BY DR GERRI FRAGER, NOVA SCOTIA, CANADA WITH KIND PERMISSION OF JENICA SAULNIER'S FAMILY.**



## **SECTION ONE: SUFFERING AT THE END OF LIFE – IS IT INEVITABLE?**

Living with, and dying from a disease such as cancer or AIDS is usually a devastating experience that is not restricted by age group, social status or way of life. The pain and trauma, both physical and psychological, of dying of a progressive terminal illness are indiscriminate, shattering the lives of children, young adults and elderly people alike, whoever they are and wherever they live in the world.

The impact extends beyond the person that is dying to many of those with whom they have contact, including family, friends and other dependents. These individuals face significant changes in their lives during and after the course of the illness, such as the loss of an important relationship and the end of practical, emotional and financial support and security.





The impact of AIDS on children is complex and multi-faceted.

WALL OF REMEMBRANCE AT SUNFLOWER HOSPICE, SOUTH AFRICA



## **SECTION ONE: SUFFERING AT THE END OF LIFE – IS IT INEVITABLE?**

### **FACTS AND FIGURES**

There are currently more than 13 million children under 15 years of age who have lost one or both parents to AIDS. Most live in sub-Saharan Africa. By 2020, the number is expected to increase to more than 25 million<sup>[6]</sup>. AIDS brings psychosocial distress and material hardship to children. They may be pressed into service to care for ill and dying parents, required to drop out of school to help with farm or household work, or experience declining access to food and health services. Many are at risk of exclusion, abuse, discrimination and stigma.

## SECTION ONE: SUFFERING AT THE END OF LIFE – IS IT INEVITABLE?



**ARDEN AND HER DAUGHTER WITH  
MEMBERS OF THE HOSPICE TEAM**

### **ARDEN'S STORY**

Arden was born in Malaysia, but has lived in the USA for many years. She has been receiving palliative care for the last three years, during each of her hospital admissions for cancer treatment. This care has been provided by physicians, nurses, social workers and massage therapists who have been working to relieve her physical symptoms, as well as any psychological and spiritual suffering. They have also offered support to her family and friends. In particular they have sought to ensure that Arden's teenage daughter will be placed in a loving environment after Arden's death and have also tried to secure a visa for Arden's sister, who lives in Malaysia, to emigrate to the United States to help care for Arden and her daughter.

The palliative care team has worked closely with the oncology team to tailor a discharge plan that will combine chemotherapy with palliative care, thereby reducing any symptoms experienced by Arden and assuring her maximum quality of life. Arden has particularly valued the holistic nature of her care, as have her family and friends, who feel that their own needs have been met as well as Arden's.

**STORY PROVIDED BY THE MOUNT SINAI MEDICAL CENTER'S INPATIENT PALLIATIVE CARE CONSULT SERVICE IN NEW YORK.**



## SECTION ONE: SUFFERING AT THE END OF LIFE – IS IT INEVITABLE?

Palliative care has the potential to be used more widely than at present, to alleviate suffering common to a range of serious diseases. For example, pain and symptom control, so effectively used in care of cancer or AIDS, could also be used for other diseases. The potential has only recently begun to be explored.

### FACTS AND FIGURES

The table summarises the findings of 64 studies and shows the symptoms experienced by patients with specific diseases <sup>(7)</sup>. Each box shows the smallest and greatest percentage of patients affected.

### PREVALENCE OF SYMPTOMS IN CANCER AND OTHER DISEASES

Symptoms	CANCER	AIDS	HEART DISEASE	*COPD	RENAL DISEASE
Pain	35-96	63-80	41-77	34-77	47-50
Depression	3-77	10-82	9-36	37-71	5-60
Anxiety	13-79	8-34	49	51-75	39-70
Confusion	6-93	30-65	18-32	18-33	?
Fatigue	32-90	54-85	69-82	68-80	73-87
Breathlessness	10-70	11-62	60-88	90-95	11-62
Insomnia	9-69	74	36-48	55-65	31-71
Nausea	6-68	43-49	17-48	?	30-43
Constipation	23-65	34-35	38-42	27-44	29-70
Diarrhoea	3-29	30-90	12	?	21
Anorexia	30-92	51	21-41	35-67	25-64

\*COPD = chronic obstructive pulmonary disease

## **SECTION TWO**

### **SUFFERING AT THE END OF LIFE – A PICTURE OF INEQUALITY**

#### **MARTHA'S STORY**

The door of the hut opens in. The hut, partitioned in three, sleeps the whole family. Martha is lying on her bed covered in one blanket. The wooden slats of the hut do not join evenly, and one has been removed to let more light in. There are some chickens scraping on the earthen floor under the bed. There is no running water and no electricity in the compound.

Martha lies on a thin foam mattress; it has no cover or sheet and is stained. There is no pillow; Martha is resting her head on her arm. She greets us, pleased, in the midst of her pain, to have company.

Martha knows she has cancer, and knows she will die. She confides in us that she is waiting daily to be relieved of the pain and to go to heaven. She begins to talk of the past. She wished she had gone to the hospital earlier; instead, she had tried small remedies from cheaper private little clinics dotted all over the hillsides in the area. When she finally saw a doctor she was told her illness could not be stopped and was sent home from hospital with some morphine. It had finished long ago, but there was no money in the family after paying the hospital bill, so no more was purchased.

Over the last few weeks her condition has changed, and her world has changed too. No longer able to move out of bed, she is faced with no alternative but to pass urine and stool on to rags torn from her clothes. Her husband carries them to the pit latrine some 100 metres away. We examine her and find an infected bedsore, which she is not mentioning.

Her husband is now doing the cooking, though Meru men traditionally do not enter the kitchen after their ritual circumcision. He waits every day at the homestead; his task is now to care for her and the two younger children, one of whom has learning disabilities.

Martha tells us how she misses the company of others and feels sad when family members and visitors come to the compound but don't enter her little room, choosing instead to sit outside and talk a little through the wooden slats. She wonders why. Is it because they find the smell of her wound too difficult to cope with? Is it because they think she has another disease? She fears that they all think she has AIDS and this is the reason they do not visit.

**WRITTEN BY ELIZABETH GRANT, DOCTOR AT CHORGORIA HOSPICE IN KENYA.**



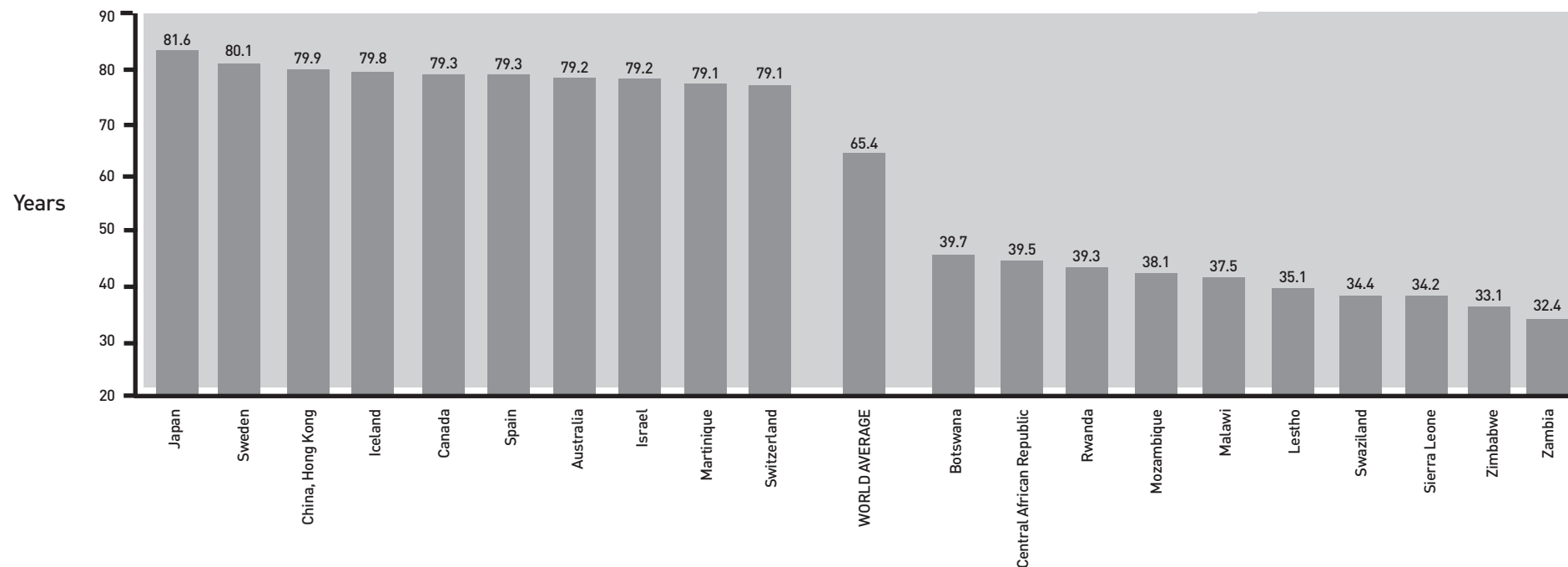
## SECTION TWO SUFFERING AT THE END OF LIFE – A PICTURE OF INEQUALITY

Nowhere is global inequality more apparent than when looking at life expectancy. People living in the least developed countries have a much lower life expectancy at birth than those in high-income countries and also a higher infant mortality rate.

Developing countries have two-thirds of the global disease burden, but only around 5% of the world's resources for controlling and combating disease, such as doctors, nurses, drugs, equipment and funds.

### FACTS AND FIGURES

LIFE EXPECTANCY AT BIRTH: COUNTRIES WITH HIGHEST AND LOWEST RATES 2000-2005<sup>(8)</sup>





A VOLUNTEER PREPARING MORPHINE AT HOSPICE AFRICA, UGANDA

**OPIOIDS ALONE ARE NOT THE SOLUTION TO THE WIDER AVAILABILITY OF PALLIATIVE CARE, BUT THEY ARE A MARKER OF PROGRESS. THEY ARE SIMPLE, CHEAP, SAFE AND EFFECTIVE.**

## **SECTION TWO SUFFERING AT THE END OF LIFE – A PICTURE OF INEQUALITY**

Morphine and other pain-killing medicines are essential to reduce suffering at the end of life. At present, there are huge differences in the availability and use of such drugs with the consumption of morphine as a prescribed medicine much lower for people living in developing countries than in developed ones.

Cost is one reason. Half the world's population lives on less than US\$2 a day <sup>(9)</sup>, so government action to make the drugs affordable is crucial. Low use is also a consequence of some governments restricting the use of morphine for medicinal purposes and lack of education or suspicion on the part of those who may prescribe it.

Given morphine's proven place in the relief of suffering, its potentially low cost and the availability of clear, simple policies and advice for its use, failure to adopt it on a wide scale is unacceptable.



### SECTION THREE

## HOSPICE/PALLIATIVE CARE – A RESPONSE TO SUFFERING AT THE END OF LIFE



PHOTOGRAPH BY BENNY GOO

“Every year, millions of people around the world living with a terminal illness suffer unnecessary pain and distress, either unaware of, or unable to access the care they need. Good quality hospice and palliative care, which aims to meet the needs of the whole person, can and does provide an answer. This is an issue that affects literally everybody on this planet – we would all like our lives to end peacefully and comfortably.”

**ARCHBISHOP DESMOND TUTU**

### **SECTION THREE HOSPICE/PALLIATIVE CARE – A RESPONSE TO SUFFERING AT THE END OF LIFE**

Hospice or palliative care has been identified as a relatively cheap and effective means of meeting the needs of those nearing the end of their lives, thereby ensuring that they do not suffer unnecessarily.

The case of Uganda shows that palliative care is not just for wealthy industrialised nations. Uganda was the first African country to make palliative care for people with AIDS and cancer part of its national health plan (2000–2005). A clear national policy has been established, with appropriate education for health professionals at all levels. Affordable morphine has been made easily available in the country. <sup>(1)</sup>



**A PALLIATIVE CARE PATIENT FROM HOSPICE IN AUSTRALIA SUPERVISES HIS CHILDREN AS THEY TAKE OVER THE FARM**



**PALLIATIVE CARE AT HOME IN BELARUS**



**A DAY CARE PATIENT IN TRINITY HOSPICE UK RECEIVING REFLEXOLOGY**

**A PATIENT IN KERALA WITH HIS FAMILY WHO PLAY A KEY ROLE IN DECISIONS ABOUT MANAGING HIS CONDITION**



**ACTIVITIES AT THE INANDA DAY CENTRE, ZIMBABWE**





### **SECTION THREE HOSPICE/PALLIATIVE CARE – A RESPONSE TO SUFFERING AT THE END OF LIFE**

Traditionally, hospice or palliative care is provided by a multi-disciplinary team of professionals, supported by trained volunteers. It is available in a variety of settings – at home, in hospital, in care homes, hospice inpatient units or day hospitals. Although the definition of palliative care is globally relevant, its form will vary according to local conditions. For example, evidence from sub-Saharan Africa shows that palliative care needs and services are affected by poverty and HIV.

The care takes many forms, including skilled medical and nursing care, rehabilitation, counselling, creative activities, complementary therapies (such as massage or aromatherapy) and social support. Often the terminally ill person and their family use different services as the illness progresses. Their involvement in planning and evaluating this care is central to ensuring that it meets their needs. However, research has shown that the necessary components of palliative care include practical, pain and symptom control, counselling/emotional/psychological support, income generation, financial support for food, shelter, funeral costs and school fees, respite, spiritual support and orphan care. <sup>(10)</sup> It is often the case that care for the family continues after the death of the patient, helping them through their bereavement.



**A PATIENT OF THE WOMEN'S GUILD PALLIATIVE CARE PROGRAMME OF CHOGORIA HOSPITAL, KENYA, WITH HER CHILDREN**



**HOSPICE VOLUNTEERS AT CASA SPERANTEI, ROMANIA, TAKING THREE BROTHERS ON AN OUTING**



**ONE OF THE FIRST PATIENTS TO BE ADMITTED TO HOSPICE HOUSE, HUNGARY**



**VOLUNTEER STUDY DAY AT HOSPICE IN KERALA, INDIA**



**A HOME VISIT BY THE BEDOUIN MOBILE PALLIATIVE CARE UNIT, NEGEV REGION, ISRAEL**

### **SECTION THREE HOSPICE/PALLIATIVE CARE – A RESPONSE TO SUFFERING AT THE END OF LIFE**

High quality palliative care utilises opioid drugs to control pain and is sensitive to local cultural traditions, beliefs and ethics.

The best way to develop effective palliative care is based on a combination of activities – clinical care, education and research – each one informing the others.

Meeting the global need for palliative care is an enormous, yet vital task. Its achievement requires individual countries to adopt a strategic and systematic approach to the development of such care, and to work collaboratively at local, national and international levels.

#### **FACTS AND FIGURES**

It is estimated that in an ideal world 100 million people could benefit from basic palliative care. This number is made up of over 33 million dying people (60% of the total number dying in the world each year) and their 66 million family members, companions or carers (based on a conservative estimate of 2 people giving care and support for every person that dies <sup>(1)</sup>).



## GLOBAL PROVISION OF PALLIATIVE CARE



MERU HOSPICE, KENYA

**IT IS ESTIMATED THAT HOSPICE OR PALLIATIVE CARE SERVICES NOW EXIST, OR ARE UNDER DEVELOPMENT, ON EVERY CONTINENT, IN AROUND 100 COUNTRIES.**

**THE TOTAL NUMBER OF HOSPICE OR PALLIATIVE CARE INITIATIVES EXCEEDS 8,000. THESE INCLUDE INPATIENT UNITS, HOSPITAL BASED SERVICES, COMMUNITY-BASED TEAMS, DAY CARE CENTRES AND OTHER MODES OF DELIVERY.**

## **SECTION FOUR**

### **GLOBAL HOSPICE/PALLIATIVE CARE – THE WAY AHEAD**

The last 50 years have seen the emergence of modern hospice and palliative care services in many parts of the world. In some countries palliative care is recognised as a health care speciality and is supported by extensive education programmes, research and academic enquiry. In others it is still in its infancy, characterised by small local projects arising from the passion and commitment of one or two individuals, who work in a context of few resources with limited government support. However, in many other countries, there is no evidence even of early initiatives to provide hospice or palliative care, and no signs that this deficit is being addressed at national level.

Even in countries where palliative care services have been established for some time, opportunities exist to improve and extend them. There is evidence of uneven access for some groups of people, inadequate funding of services and lack of national policy relating to palliative care. Furthermore, palliative care still tends to be limited largely to AIDS and cancer sufferers and needs to be available to those affected by other diseases.

The number of people needing palliative care is likely to increase:

- The world's population is growing and is also ageing.
- More people have serious chronic illness towards the end of life.

## **SECTION FOUR GLOBAL HOSPICE/PALLIATIVE CARE – THE WAY AHEAD**

### **THE ROLE OF GOVERNMENT**

Government's role in developing and promoting palliative care is crucial. Hospice and palliative care associations from around the world drew up a Declaration on Hospice and Palliative Care <sup>(2)</sup> in March 2005 which asked governments to take fifteen actions. They include the following:

- Include hospice and palliative care as part of all governmental health policy, as recommended by the World Health Organization.
- Make access to hospice and palliative care a human right.
- Make resources available for hospice and palliative care programmes and services.
- Make necessary drugs available, including affordable and available morphine to the poorest.

The global community must act now to meet the enormous challenge of providing palliative care for all who need it. To ensure suffering at the end of life is not inevitable, let each and every one of us play our part. We all stand to benefit.



#### SECTION FOUR GLOBAL HOSPICE/PALLIATIVE CARE – THE WAY AHEAD



THE GARDENS AT SHANTI AVEDNA SADAN, DELHI

Go round and see what is being done and then see how your own circumstances can produce another version; there is need for diversity in this field.

DAME CICELY SAUNDERS IN ESSENTIALS FOR A HOSPICE, 1976

## SECTION FOUR GLOBAL HOSPICE/PALLIATIVE CARE – THE WAY AHEAD

If you are wondering how to get started in palliative care, how to get new ideas and increase your knowledge or who to turn to, the following is a select list of key contacts and resources that will signpost you to further information.

### LOCAL AND REGIONAL

Contact your local palliative care services

National Associations website: [www.hpc-associations.net/](http://www.hpc-associations.net/)

AFRICA	African Palliative Care Association <a href="mailto:info@apca.co.ug">info@apca.co.ug</a>
ASIA	Asia Pacific Hospice Network <a href="http://www.aphn.org">www.aphn.org</a>
AUSTRALASIA	Palliative Care Australia <a href="http://www.pallcare.org.au">www.pallcare.org.au</a> Hospice New Zealand <a href="http://www.hospice.org.nz">www.hospice.org.nz</a>
N AMERICA	National Hospice Palliative Care Organization <a href="http://www.nhpco.org">www.nhpco.org</a> Canadian Hospice Palliative Care Association <a href="http://www.chpca.net">www.chpca.net</a>
LATIN AMERICA	Asociación Latinoamericana de Cuidados Paliativos <a href="http://www.cuidadospaliativos.org">www.cuidadospaliativos.org</a>
EUROPE	European Association for Palliative Care <a href="http://www.eapcnet.org">www.eapcnet.org</a> Eastern and Central Europe Palliative Care Task Force (ECEPT) <a href="http://www.oncology.am.pozan.pl/ecept/">www.oncology.am.pozan.pl/ecept/</a>

## **SECTION FOUR GLOBAL HOSPICE/PALLIATIVE CARE – THE WAY AHEAD**

### **GLOBAL**

The Center to Advance Palliative Care (CAPC) [www.capc.org](http://www.capc.org)

Help the Hospices' UK forum for hospice and palliative care worldwide [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)

International Association for Hospice and Palliative Care (IAHPC) –  
key resources include the Manual of palliative care and Getting Started [www.hospicecare.com](http://www.hospicecare.com)

The International Observatory on End of Life Care [www.eolc-observatory.net](http://www.eolc-observatory.net)

### **POLICY, DRUGS AND PAIN CONTROL**

The Pain and Policy Studies Group (PPSG), University of Wisconsin, is the designated World Health Organization (WHO) collaborating Center for Policy and Communications in Cancer care. This site will link you to all essential WHO publications and other relevant sites [www.medsch.wisc.edu/painpolicy](http://www.medsch.wisc.edu/painpolicy)

Essential independent information for health professionals about the use of drugs in palliative care can be found at [www.palliativedrugs.com](http://www.palliativedrugs.com)

### **EDUCATION AND TRAINING**

Local, national and regional education providers

Academic centres. Check it out at [www.hospiceinformation.info](http://www.hospiceinformation.info) –

look under Training or request a copy of our electronic directory of education and training, eChoices (A global database of Education and Training is under construction.)

### **FUNDING**

Potential funders for hospice and palliative care services in developing and transitional countries, Help the Hospices 2005. Available to download from [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)



## SECTION FOUR GLOBAL HOSPICE/PALLIATIVE CARE – THE WAY AHEAD

### INFORMATION AND LIBRARY RESOURCES

Halley Stewart Library, St Christopher's Hospice, will provide references on bereavement, cancer and other diseases [www.stchristophers.org.uk](http://www.stchristophers.org.uk) **Email:** [d.brady@stchristophers.org.uk](mailto:d.brady@stchristophers.org.uk) **Fax:** + 44 (0)20 8776 9345

PubMed, a service of the National Library of Medicine, is a major international medical and nursing bibliographic database – free of charge at [www.ncbi.nlm.nih.gov/entrez](http://www.ncbi.nlm.nih.gov/entrez)

**hospice information** offers enquiry service, free membership to resource-poor countries, publications (electronic and print) and networking.

**Free newsletters** - a range of electronic and printed newsletters will help you to keep up to date with international palliative care - download a list from [www.hospicecare.com](http://www.hospicecare.com) (Publications)

### CHILDREN'S HOSPICE/PALLIATIVE CARE

The International Children's Palliative Care Network (ICPCN) is a global network of children's hospice and palliative care services [www.icpcn.org](http://www.icpcn.org)

### HIV/AIDS

UNAIDS produce a series of HIV palliative care and HIV management education resources and reports available at [www.unaids.org](http://www.unaids.org) or on CD-ROM

Aegis HIV information and resource website. Includes clinical and treatment and a large, searchable database for information and reports. [www.aegis.com](http://www.aegis.com)

For other common disease groups requiring palliative care please refer to Information and Library Resources

For reasons of space this is simply an attempt to signpost you to essential resources. If you cannot find the information you need please contact **hospice information** at the address below.

This list is compiled by **hospice information**, a joint venture between St Christopher's Hospice and Help the Hospices.

**Telephone:** +44 (0)870 903 3 903 **Fax:** +44 (0)8776 9345

**Email:** [info@hospiceinformation.info](mailto:info@hospiceinformation.info) **Website:** [www.hospiceinformation.info](http://www.hospiceinformation.info)

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## ACKNOWLEDGEMENTS

This publication was produced in partnership with national and pan-national hospice and palliative care associations around the world. The editorial and production team consisted of staff at Help the Hospices, Dr Richard Harding at Kings College London, and Rose Heatley.

We would like to offer special thanks to all those volunteers and professionals working in and with palliative care initiatives across the world who offered photographs, case studies and facts for this report, not all of which we have been able to include. We could not have done this without their help, advice and contributions. Below is a list of those organisations whose photographs and case studies have been included.

Belarussian Children's Hospice, Belarus  
Cicely Saunders Foundation, UK  
Coalition of Service for the Elderly, Philippines  
Highway Hospice Association, South Africa  
Home Palliative Care Service, Israel  
Hospice & Palliative Care Association, South Africa  
Hospice Africa, Uganda  
Hospice of Hope and Casa Sperantei, Romania  
Hungarian Hospice Foundation  
Institute of Palliative Medicine, Kerala, India  
IWK Grace Health Centre, Nova Scotia, Canada  
Meru Hospice, Kenya  
Mount Sinai Medical Centre, New York, USA  
Palliative Care Australia  
Shanti Avadna Sadan, New Delhi, India  
Trinity Hospice, UK  
Uruguayan Society of Palliative Care, Uruguay  
Women's Guild Palliative Care Programme, Chogria Hospital, Kenya

ISBN Number 1 871978 49 1

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Eastern and Central Europe  
Palliative Task Force